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### NEWS FROM EDSA MEMBERS

FUNDACIO' CATALANA SINDROME DE DOWN (SPAIN)



Intellectual disability and cognitive impairment in Down syndrome. From birth to old age.  
Barcelona, November 26th-27th, 2015  
Hotel Arts (c/ Marina 19-21)

The Congress is organized by the Fundació Catalana Síndrome de Down with the aim of reflecting and giving a comprehensive view on intellectual disability and cognitive impairment associated with Down syndrome. Different specialists will address the challenges, diagnoses, treatment and research on intellectual disability and the age associated cognitive impairment, especially that produced by Alzheimer's disease in Down syndrome. During the conference we will present the winner of the XIV Ramon Trias Fargas Biennial Award for Research.

The Conference will feature prominent professionals from leading national and international Down syndrome foundations such as the Institut Jérôme Lejeune, France; the Radboud University Medical Centre, The Netherlands; the LonDowns Consortium, United Kingdom; or the Centre for Genomic Regulation, Spain; as well as leading Alzheimer's disease research centers such as Hospital de la Santa Creu i Sant Pau, Spain; the University Medical Center Groningen, The Netherlands; the University College London, United Kingdom, or Fundació ACE (Spain).

There will be several lectures on medical and scientific advances related to the intellectual disability and cognitive impairment associated with Alzheimer's disease with two keynote lectures by Dr. Rafael Blesa, Director of the Neurology Service of Hospital de la Santa Creu i Sant Pau, and Dr. Jesús Flórez, President of the Fundación Iberoamericana Down21.

We will also hold interactive workshops with people with Down syndrome and their families to enrich the debate and inform on all health and social resources at their disposal, which can improve the quality of life of the persons and patients with Down syndrome.

[Click here for Program, registration form and more information.](#)

## WHAT'S NEW?!

### THE INTERNATIONAL ARTS CONTEST "PLAY WITH ME" FEBRUARY 2016

Cankarjev dom - Culture and Congress Centre  
Ljubljana, Slovenia



In the framework of the Festival year »Play with me« the International Arts Contest »Play with me« is traditionally held again this year. The opening exhibition of the International Arts Contest "Play with me" will be held in Cankarjev dom, in February 2016 and will include the setting up of the received works, the opening of the exhibition and a varied animation program.

The exhibition will later travel to different cities around Slovenia and last year alone we received 5069 art works from Slovenian schools and institutions and from abroad. We invite you to take part in the contest that is this year dedicated to two subjects:

- First being the traditional: PLAY WITH ME (you can play alone – with toys, dancing, doing sports, playing on the computer or you can play with friends – schoolmates, grandparents, teachers, animals, ... you can play at home, at a playground, in the woods, on the street, ...)
- The second subject: I LIKE HELPING (you can help your family, your friends, help in trouble, volunteer, ...)

You can enter the open call by filling out the [online application](#) (in Slovene) or mail us the information about the participants and their works to [bodiunik@igrajsezmano.si](mailto:bodiunik@igrajsezmano.si) and then send us the work by mail (more information in the attachment).

The hand-in deadline is the 15th of December 2015.

Contact and additional information:

- phone: 00386 1 2418 125 workdays between 12.00 and 14.00
- email: [bodiumetnik@igrajsezmano.si](mailto:bodiumetnik@igrajsezmano.si)

## NEWS FROM EUROPEAN PROGRAMMES

ERASMUS PLUS: New programme guide and next deadlines!

The conditions for participation in 2016 are described in the latest version of the Erasmus+ Programme Guide: it's an integral part of the 2016 Erasmus+ Call for Proposals and its corrigendum , published on 22/10/2015.

Organisations and institutions seeking funding in the framework of this call must comply with the conditions for participation and funding expressed in this Guide.

The document provides information on:

- the priorities of the programme,
- the actions supported,
- the funding available for different actions,
- detailed information on participation.

### Deadlines for submission of application

Key Action	Activity	Sector	Deadline
Key Action 1: Mobility of individuals	Learning mobility of individuals	Higher education, vocational education and training, schools, adult education	2 February 2016, 12am (Brussels time)
		Youth	2 February 2016, 12am (Brussels time) 26 April 2016, 12am (Brussels time) 4 October 2016, 12am (Brussels time)
Key Action 2: Co-operation for innovation and the exchange of good practices	Strategic partnerships	Higher education, vocational education and training, schools, adult education, and applications for strategic partnerships in more than one field including youth.	31 March 2016, 12am (Brussels time)
		Youth	2 February 2016, 12am (Brussels time) 26 April 2016, 12am (Brussels time) 4 October 2016, 12am (Brussels time)
Key Action 3: Support for policy reform	Structured dialogue	Youth	2 February 2016, 12am (Brussels time) 26 April 2016, 12am (Brussels time) 4 October 2016, 12am (Brussels time)
VET Mobility Charter*	Learning Mobility of Individuals	Vocational education and training	19 May 2016, 12am (Brussels time)

Organisations are invited to submit applications on-line to the National Agency in the relevant country or to the Education, Audiovisual and Culture Executive Agency.

The 2016 on-line application forms and related documents are currently being prepared and will be available on websites of either the National Agencies or the Education, Audiovisual and Culture Executive Agency, depending on the actions concerned.

### EUROPE FOR CITIZENS

The programme “Europe for Citizens”, which applies for the whole duration of the Programme 2014 - 2020, intends to guide all interested persons through the different aspects of the programme.

For information about the programme:

[http://eacea.ec.europa.eu/europe-for-citizens\\_en](http://eacea.ec.europa.eu/europe-for-citizens_en)

## Deadlines for submission of applications

*Action 1 European remembrance*  
01/03/2016 12:00 (CET/CEST)

*Action 2 Democratic engagement and civic participation*  
Network of towns 01/03/2016 12:00 (CET/CEST)  
Town twinning 01/03/2016 12:00 (CET/CEST)  
Civil society projects 01/03/2016 12:00 (CET/CEST)  
Network of towns 01/09/2016 12:00 (CET/CEST)  
Town twinning 01/09/2016 12:00 (CET/CEST)

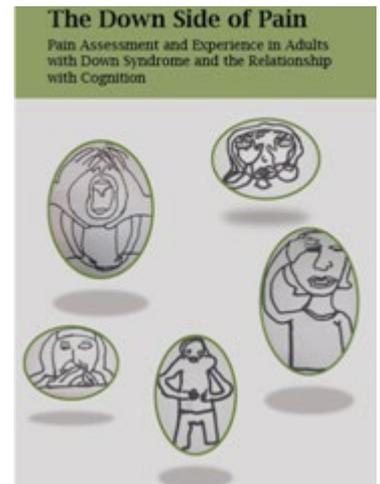
## A CLINICAL RESEARCH

THESIS ABOUT PAIN IN ADULTS WITH DOWN SYNDROME  
a summary of main findings

**Nanda de Knegt**, Postdoctoral researcher (pain perception and cognition in people with intellectual disabilities) Free University, Department of Clinical Neuropsychology, Amsterdam

### REVIEW SECTION

A literature review showed that musculoskeletal disorders occur in all of the seven included subtypes of intellectual disabilities (i.e., syndromes): Down syndrome (DS), Prader-Willi syndrome, Williams syndrome, Fragile-X syndrome, Rett syndrome, cerebral palsy, and 22q11.2 Deletion Syndrome. Examples of musculoskeletal disorders were scoliosis, arthritis, and instability or dislocation of the joints. It has virtually not been examined how much pain the presence of musculoskeletal disorders causes in these subtypes of intellectual disabilities, while adults in the general population rate some musculoskeletal disorders as being painful.



Experimental pain studies show a delayed verbal response to heat and cold induced pain and a lower heat-pain threshold in people with DS, in contrast to a higher heat-pain threshold pain in Prader-Willi syndrome. On the basis of characteristic neuropathology in pain-related brain areas and pathways, a higher pain experience may be expected in Fragile-X syndrome and 22q11.2 Deletion Syndrome, while pain experience could be both increased and decreased in DS, Williams syndrome, and Prader-Willi syndrome.

In a systematic review, most of the 27 studies about behavioural pain indicators in people with intellectual disabilities had a methodological quality of 50% on a scale from 0 to 100%. Fourteen categories of behavioural pain indicators were defined, of which motor activity, facial

activity, social-emotional indicators, and non-verbal vocal expression were the most frequently reported. Still, it is not always clear that the observed behaviour is caused by pain instead of related factors (e.g., stress or fear) and behavioural pain indicators could differ per individual. Behavioural pain indicators that were found in (young) adults with DS were facial pallor, restlessness, excessive talking, response to analgesics, and exaggeration of usual symptoms of the disability.

## CLINICAL SECTION

After the literature reviews, the next step was to investigate approaches and tools to aid pain assessment in adults with DS. When the comprehension of a numeric scale was assessed thoroughly by not only asking which numbers represent the least pain (0 or 1) and the most pain (9 or 10) but also asking questions about the magnitude of numbers ('Which is larger: 2 or 8?' and 'Which is larger: 6 or 4?'), then fewer adults with DS passed the comprehension test. Differences in comprehension and preference for facial pictograms as compared to drawn faces were not statistically significant. Half of the participants understood a series of pictograms for sensory-discriminative quality of pain (burning, stinging, throbbing, and pressing). The current version of an online application for screening of pain experience is too difficult for adults with DS to use without assistance and especially the use of a computer mouse is complex.

The subsequent step was to investigate spinothalamic-mediated sensory functions (i.e., temperature, pain, and crude touch) and pain experience in adults with DS. Adults with DS were as able as adults from the general population to discriminate with closed eyes warm and cold and to feel monofilaments on the forearms. Adults with DS with a lower intelligence level were less able than adults from the general population to discriminate sharp from dull. More participants with DS (50%) than adults from the general population (35%) had physical conditions that could cause pain or discomfort. However, fewer participants with DS (58%) than adults from the general population (73%) reported pain during the test session. Of the participants who reported pain, the average pain experience (i.e., reported by using a facial scale and a numeric scale) was higher in the DS group than in adults from the general population. Adults with DS comprehended the facial scale (75%) better than the numeric scale (43%) and almost 80% comprehended at least one of these scales. While controlling for age, gender, language comprehension, vocabulary, and the presence of possible painful or discomforting conditions, adults with DS with a worse memory were more likely to report pain. No statistically significant association was found between cognitive functioning and pain



experience. The presence of the ApoE ε4 allele in adults with DS did not have a statistically significant association with pain experience or with the relationship between pain experience and cognition, but had a statistically significant association with a worse executive functioning.

## ONE GOOD OPPURTUNITY FOR EDSA MEMBERS

ROSETTA FOUNDATION:

access to information to as many people as possible

Since 2009, The Rosetta Foundation has worked to eradicate the knowledge gap based on linguistic discrimination with the support of friends and colleagues in the translation and localisation industries. It helps to connect language volunteers with non-profit organisations that work with under-served communities. Together with these organisations, the Rosetta Foundation aims to create access to language services that were previously unavailable to linguistically marginalised communities.

The work done by the Rosetta Foundation with volunteers and organisations through the [Translation Commons \(Trommons\)](#) allows these communities better access to knowledge and information around justice, education, healthcare, and economic wellbeing. Over 10,000 volunteers covering 115 languages are now registered to help Rosetta Foundation's 244 non-profit partners.

AIPD has already involved the Rosetta Foundation with translation and proof - reading of different documents and has recently invited it to join a project proposal in the framework the European Daphne Programme ([www.therosettafoundation.org/blog/translation-brings-empowerment/](http://www.therosettafoundation.org/blog/translation-brings-empowerment/)).

For further information: [www.therosettafoundation.org](http://www.therosettafoundation.org)

## INTRODUCING A NEW EDSA MEMBER

DOWN SYNDROME ALBANIA FOUNDATION (DSA)

Down Syndrome Albania (DSA) Foundation is a not for profit foundation, with social purposes on the field of human rights, health, and education for individuals with Down syndrome and for their families. The members of Board of Directors and the Executive Director of DSA are parents of children with Down syndrome.

**Vision:** Full inclusive, independent life for individuals with Down syndrome in Albania, and parents with exceeded expectations for their children.

**Mission:** Commit to promote and support the legitimate right of acceptance, inclusion and integration of people with Down Syndrome in Albanian society, based on Human Rights Convention and on Convention on the Rights of Persons with Disabilities, by informing and raising awareness towards public opinion, decision-making institutions and other stakeholders, and to contribute to the

development of the maximum potential of individuals with Down syndrome, in succeeding to live an independent and inclusive life, by promoting and applying the most contemporary educational and therapeutic methodologies.

Objectives of DSA activities:

1. To provide information, orientation and trainings for families, caregivers, nurseries, teachers and other professionals who work with children and individuals with Down syndrome.
2. Raising awareness toward public opinion about Down syndrome and the potential of individuals with this syndrome to be valuable and active members in the society.
3. Representation of individuals with Down syndrome.
4. Therapeutic support and education for children and adults with Down syndrome.
5. Support for parents of children with Down Syndrome.

#### “ACHIEVEMENT AND DEVELOPMENT CENTER” OF DOWN SYNDROME ALBANIA FOUNDATION

The establishment of the DSA “Achievement and Development Center”, came as a result of fulfilling the need of a “one stop point” service for children, individuals with Down syndrome and for their parents. The existence of our center became a reality thanks to the financial investment of Raiffeisen Bank and of the in-kind contribution of TIKA (Turkish Cooperation and Coordination Agency), Albanian Mobile Communication, Unifers Reklama and PAS+P Marketing. The main purpose of the center is to offer early intervention therapies for children with Down syndrome, as the most effective way in early childhood for helping the child to develop their potential. Early childhood therapeutic intervention is the “A” to reach “Z” or in other words, it is a necessary step to invest in the development of the maximum potential of people with Down syndrome so they can achieve to have a healthy, independent and inclusive life.

Early intervention program is targeted to children with Down syndrome from birth to five years of age and to their families. Its primary goals are:

- to help families in supporting their child development;
- to promote child development in vital domains;
- to promote child coping confidence; and
- to prevent the emerge of future problems.



According to the above, within the concept of Early Intervention Program, in our center we offer:

### **Assessments**

- Psychological assessment
- Speech and language assessment
- Physical assessment
- Assessment of skills and independence (autonomy) of individual with Down syndrome

### **Therapeutic services for children with Down Syndrome**

- Speech and language therapy
- Physical therapy
- Developmental and occupational therapy
- Life skills for individuals over 16 years of age
- Music therapy and art therapy

### **Parent support**

- Psycho-education for parents
- Group therapy for parents
- Individual counseling
- Offering valuable literature about DS in Albanian and in foreign languages
- Legal counseling for parents which face problems and injustice in their efforts to ensure a healthy life, education in inclusive environment, life skills and employment for their children and a life financial supported through the National Social Service scheme.



You can find us:

Address: St. "Xhon Kenedi", Selita 5 (50 m after underpass with direction on "Kodra e Diellit" residence).

Web: [www.dsalbania.org](http://www.dsalbania.org)

e-mail: [info@dsalbania.org](mailto:info@dsalbania.org)

Mobile: +355 68 80 44 999, +355 68 80 42 222

Facebook/DownSyndromeAlbania

### MAKE THIS NEWSLETTER REALLY YOURS!

Have you got any news that we could publish in EDSA newsletter? Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

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European Down Syndrome Association

**edsa**